

ANNUAL REPORT 2017 — 2018





Who are We?

Our mission: Working towards the best possible lives for Fragile X families throughout Australia

Fragile X Association of Australia (FXAA) is a national member-based charitable organisation dedicated to improving the health and wellbeing of those affected by Fragile X syndrome and other Fragile X-associated Disorders. We have been serving the Fragile X community for almost 30 years by offering support, service, knowledge, and connections. Our current member base is 325, including individuals and organisations.

We provide specialised information, a Help Line 5 days per week, counselling and family support, referrals, educational workshops and seminars, and facilitate access to assessment clinics. We have a comprehensive website, and we leverage social media to provide information, peer support, and advocacy. We work to increase awareness of Fragile X-associated disorders in the medical and wider community to promote early diagnosis and early interventions and treatments. We serve as a voice for those affected by Fragile X.

FXAA receives no public funding and therefore donors, grants, in-kind contributions and substantial volunteer input sustain our role and the support and services we can provide.

Our commitment is to be responsible and responsive, operating within our means to help meet the needs of members and participate in ongoing and emerging initiatives for disability, health and wellbeing and the particular issues of genetic conditions. The underlying principles which guide us:

Service, Respect, Accountability, Evaluation, Compliance



Photo credits cover and page 2: Daniel Linnet of **LinnetFoto**, for Fragile X Association of Australia

Understanding Fragile X

Fragile X-associated Disorders are caused by an alteration or change to the FMR1 gene on the X chromosome. Fragile X-associated disorders are inherited from a parent who 'carries' the altered FMR1 gene. This gene can be passed on by either parent. It is estimated that 100,000 people in Australia are affected by Fragile X in some way, as carriers of the Fragile X premutation or with Fragile X syndrome. 1 in 800 males and 1 in 170 females are premutation carriers of Fragile X, and therefore have the potential to pass this on to their children.

Fragile X syndrome Fragile X syndrome is the leading cause of inherited intellectual disability and

the most common known single gene cause of autism spectrum disorder. An estimated 1/3600 males and 1/4000-6000 females have Fragile X syndrome.

FXTAS Fragile X-associated Tremor Ataxia syndrome is a neurological condition with

symptoms including intention tremor, gait issues, short-term memory loss and cognitive decline. In later life it can affect men and some women who are

Fragile X premutation carriers.

FXPOI Fragile X-associated Primary Ovarian Insufficiency may lead to reduced fertility

and/or early menopause. FXPOI affects around 25% of women who are

Fragile X premutation carriers.

FXAND Fragile X-associated Neuropsychiatric Disorders (FXAND) is the name proposed

at the National Fragile X Foundation (US) conference in July 2018 to describe the neuropsychiatric disorders which are the most common problems associated with the Fragile X premutation, affecting approximately 50% of

individuals with 55-200 CGG repeats in the FMR1 gene.

Registered office of Fragile X Association of Australia Inc

Suite 204 20 Dale Street Brookvale NSW 2100

ABN 18 655 264 477 ARBN 626 478 966



Contents

Section	Page
Who are We?	2
Board and Team in 2017-2018	4
Board Report	5
Our Supporters	6
Family Support and Counselling	7
Website and Social Media Communications	7
Fragile X Disorders: Don't Miss Them	8-9
Fundraising Highlights	10
Workshops and Seminars	11
Financial Overview	12
Financial Statements	13-28



























Our Board 2017-2018



Katherine Brown

(South Australia)

Finance industry
Katherine has a young son who has Fragile X syndrome. Katherine is a carrier of the Fragile X premutation. Katherine is a keen runner and has raised funds for the Association through running and other events. She has served on the Board since 2015.



Prof Wm Ted Brown MD (New South Wales)

Retired director of the NY State Institute for Basic Research in Developmental Disabilities. Much of his 35-year research career has focused on Fragile X syndrome and autism. Prof Brown relocated to Australia in 2017. He joined the Board in 2018.



Graham Hook

(Queensland)

Defence industry manager

Graham has an adult son, James, who is affected by Fragile X syndrome. Graham is a keen photographer, artist and cyclist. He rejoined the Board in 2016, having previously served in several roles in the early days of the Association.



Christine Kelleher

(New South Wales)

Christine has been involved with the Association for almost 20 years as a member and as a director. She is the mother of 3 children, 2 of whom have Fragile X. Christine rejoined the Board in 2018 as Secretary, having previously served on the Board in other roles.



Judith Lenart

(New South Wales)

Investment consultant and community volunteer

Judith is qualified in urban valuation, natural health and school trusteeship and is trained in governance. Judith rejoined the Board in 2018 as Treasurer and Coordinator of the Board, having previously served as Secretary.



Mike Tozer

(New South Wales)

Founder of startup Exceptional; co-founder of Fragile X Hong Kong

Mike and his wife Helen have two children; their son Josiah has Fragile X syndrome. Mike is very active in raising awareness of Fragile X through participation in elite running events, fundraising events, and media. He has served on the Board since 2016 and is Public Officer.

Retirements from the Board 2017/2018: Nadene Lee served on the Board October 2016-January 2018; Lisa Ryan served October 2016-February 2018; Nyleta McRae served October 2015-March 2018.

Our Team

Our team comprises Wendy, Laura and Liz. After 2 years with us, Family Support counsellor Amanda Rummery-Hoy, left in October 2018 after handing over to Liz who in late August 2018.



Wendy Bruce Executive Officer Full-time



Laura Patel Bookkeeper Part-time, 1 day



Liz Jewell Family Support Counsellor Part-time, 3 days

Our Networks



International FXTAS Consortium

FXAA is a founding member, alongside the National Fragile X Foundation (US) and MIND Institute UC Davis

Board Report

THE YEAR

It has been a privilege for the Board and our small team of staff to continue serving our members and the entire Australian Fragile X community. Throughout the year our **Help Line and Family Support** service remained well utilised, and are highly valued. We have appreciated the opportunity to host expert **seminars and workshops** in Brisbane, Hobart, Melbourne and Sydney, and to create valuable video resources from these events to provide ongoing education and support for Fragile X families.

The past year has also seen awareness of Fragile X increased significantly through diverse exposure in the media: including major mainstream media coverage of Fragile X carrier screening in late July 2017, which profiled the work of Prof Sylvia Metcalfe and Dr Jonathan Cohen. July also saw some fabulous support of Fragile X through lighting of significant landmarks across the country orange, our signature colour. Landmarks included Old Parliament House and Telstra Tower in Canberra; Melbourne Town Hall and Melbourne Star; The Treasury and city bridges in Brisbane; the Stadium in Adelaide; and several landmarks in Tasmania. Many thanks to Nyleta McRae for this initiative.

In April the highly successful ABC series documentary **Employable Me** gave major national coverage to the issue of employment inclusion for people with a disability such as autism, Tourette's syndrome and Fragile X syndrome. **Marty Campbell** played a leading role in Episode 3 and a large spike in our website traffic attested to new interest in Fragile X.

In May the Federal Budget announcement by Health Minister, Greg Hunt MP, of a large-scale **genetic carrier screening project**, named Mackenzie's Mission, garnered a great deal of public interest in screening for genetic conditions including Fragile X. Set to launch in mid 2019, this research trial will screen 10,000 couples across Australia for Fragile X, CF, SMA, and hundreds of other genetic conditions. We look forward to learning more about the program in early 2019.

OUR SUPPORTERS

Our members, friends and supporters play a truly important role in what FXAA can achieve for the Fragile X community. The Board members and staff are grateful to the many people who have made a contribution of their time, other resources, and funds over the past year. In particular, we thank: the Cunningham family for their generous and ongoing support; Dean Gardiner and Yanda Morison from Oceanpaddler for the Bridge to Beach charity partnership, and Shaw and Partners Foundation for matching funds raised; and Graham and Trish Piper for mobilising their community connections each year in support of Fragile X. We thank Calvary Community Council and Zynerba for grants which supported our seminars with Dr Marcia Braden and Prof Randi Hagerman. We thank our supporters and colleagues in the medical and research fraternity community who are pivotal in raising awareness of Fragile X disorders and in supporting our community; and we thank experts Dr Marcia Braden, Prof Randi Hagerman and Dr Jonathan Cohen for their passionate support of the FX community.

YEAR OF CHANGE

As the financial year progressed there were changes at board level as some directors discontinued for personal reasons and the governance base moved back to Sydney. We thank **Lisa Ryan**, **Nadene Lee** and **Nyleta McRae** for their contributions at Board level. It is very pleasing that director nominations for election at the 2018 AGM reflect an excellent balance of skills, age, gender and geographic spread, reflecting a strong representation of membership nationwide.

Later in 2017 our 3-year Medical Communications project concluded in a formal sense with the departure of Katrina Weir. This initiative was designed to raise awareness of Fragile X-associated disorders among GPs and selected specialists, through conferences and other opportunities, and to increase the likelihood of quick and accurate referral and accurate diagnosis. This important endeavour was initiated and made possible by the generous support of the Cunningham family. As a result, thousands of GPs and other health professionals responsible for referral and diagnosis receive current information about Fragile X disorders and testing and screening. Key and lasting achievements of this initiative include relationships with experts in areas related to Fragile X; the engagement of major GP education providers on the importance of the diagnosis of Fragile X, resulting in a strong focus on Fragile X in their products and services; and the creation of permanent online content including article and videos which generate ongoing awareness.

We are tremendously appreciative of the Cunningham family's support and of Katrina's huge contribution in ensuring outcomes of value to the FX community. We continue to pursue increased focus on the range of Fragile X disorders and we're working to sustain the benefits of the project, in particular with our relationship with Healthed.

A further recent change in staffing is the departure of Family Support worker Amanda Rummery-Hoy, who worked with us for 2 and a half years in a part-time capacity as social worker/counsellor. We are most grateful to her not only for her marvellous work in this role, but also for remaining in the position to allow a comprehensive handover. In August 2018 Liz Jewell took up a newly created role which combines the community support and counselling with project work. Liz has already become a key member of the FXAA team engaged in providing Help Line support for those callers in need of FX related information, guidance, referral and understanding.

We are fortunate to retain **Laura Patel** as book-keeper and diligent minder of the numbers, and **Wendy Bruce** as Executive Officer. Wendy has managed FXAA for 5 years and established wide connections, significantly expanding the base of stakeholders. She has a range of responsibilities and operates at many levels to maintain a credible, compliant and effective organisation. The Board recognises her vital input to sustaining stability and key relationships, especially during times of change.

Board Report

YEAR OF GROWTH

The new financial year is of course well underway, starting with awareness month in July, then with Liz joining us, followed by the visit of **Professor Randi Hagerman** to Melbourne and Sydney. We were tremendously grateful to Prof Hagerman for giving us her time and energy in delivering presentations to a range of audiences, opening a new FXTAS clinic in Melbourne, and engaging with families. The Q&A videos we filmed with Prof Hagerman across several FX topics have been viewed thousands of times on youtube and social media by an Australian and international audience. Many thanks to **Zynerba Pharmaceuticals** for grant funding supporting the costs associated with Prof Hagerman's activities in Australia for FXAA.

Along similar lines but entirely non-medical is our film project **The Fragile X Factor** that is nearing completion and will actually comprise three short pieces – one for FX families, one for fundraising, and one for public awareness. These will be launched towards the beginning of 2019, marking **FXAA's 30th year** as a national organisation.

Before then we will be conducting a **survey of the FX community** to gather detailed information and gain more insight into needs and supports so that our organisation can respond accordingly.

In the coming year we will continue our involvement in the Carrier Screening Reference group alongside representatives from the peak bodies for cystic fibrosis and spinal muscular atrophy, and the Victorian Clinical Genetic Service, with whom we recently collaborated to produce a brochure on carrier screening. We will also continue to be involved with the International FXTAS Consortium, and the premutation carrier FXTAS clinic at St Vincent's Hospital and the recently opened FXTAS clinic at Caulfield Hospital. We will maintain our close contact with the other member bodies of the International Fragile X Alliance to stay abreast of developments.

Another significant development in 2019 will be the commencement of the federal government's carrier screening trial, as Fragile X is one of the three primary conditions identified for inclusion. This program will provide an important opportunity and focus for increased awareness and the early diagnosis of Fragile X-associated disorders.

Our focus in 2018-2019 in summary is to expand our support base, grow the membership, raise the profile of Fragile X, and continue to provide support and service to the Fragile X community across Australia.

Our Supporters

Fragile X Association is extremely grateful to the businesses, community groups, families, health professionals, individual donors and indeed everyone who helped support us in our mission throughout the year.

This support remains pivotal to our ability to provide services and programs to the Fragile X community, and it underpins our efforts to increase awareness of Fragile X-associated disorders for early diagnosis, early intervention and early treatments.







Galston District Garden Club

















Family Support and Counselling

The Family Support and Counselling role continues to be an important and valued service provided to our member base and the wider Fragile X community. Many of the requests for information about Fragile X or for counselling support or referrals come through our Help Line, which is available during business hours 5 days a week. The Help Line number is prominently placed on our website, and the majority of people discover Fragile X Association for the first time from the website. Other queries and requests for support are made via the FXAA facebook pages, other social media or direct email to support@fragilex.org.au



Liz Jewell

Family support is available by phone, skype and email, and can be face to face where individuals are in Sydney. In the 6-month period 1 July—31 December 2017, the Family Support counsellor was available 2 days per week. 220 occasions of support were provided during that period to over 120 people. The Help Line queries and family support contacts cover a range of concerns and questions about Fragile X-associated disorders including:

- Support for a new diagnosis of Fragile X syndrome, FXTAS, FXPOI or Fragile X premutation
- Information on testing for Fragile X syndrome—who should be tested, what the tests involve, where testing can be done, the costs involved, and understanding test results
- Identifying and accessing appropriate referrals for community supports
- Information about accessing NDIS supports and processes
- Educational needs and supports for children and adults who have Fragile X syndrome
- Counselling, support and strategies to help manage feelings of anxiety and depression and issues of grief
- The location of health practitioners who have experience and knowledge of Fragile X
- Connecting people with others with a shared diagnosis for peer support

Liz Jewell, our Family Support Counsellor, is available Mondays, Tuesdays and Thursdays. Direct email: liz@fragilex.org.au

Phone: 02 9907 2366 or 1300 394 636

Fragile X helpline
1300 394 636

Assessment Clinics

FXAA continues to support assessment clinics for children and adults with Fragile X syndrome who attend the Fragile X Alliance clinic in Melbourne. In connection with the Fragile X Community Days in Brisbane and Hobart in late 2017 we arranged for 15 adults and children to have individual assessments with Dr Jonathan Cohen, Rashelle Cohen and Dr Marcia Braden. We also facilitate access to the FXTAS clinics at St Vincent's Hospital in Sydney and at the Caulfield Hospital (AlfredHealth) in Melbourne.

Website and Social Media

Our social media platforms, website and youtube channel provide powerful tools for creating information resources on Fragile X, and providing education and increased awareness of Fragile X.



Traffic on our website remained consistent with the previous year at around **190,500 web visits**. We saw a spike of 17,000 visits on the day the Employable Me episode featuring Marty Campbell was aired on ABC TV!



2437 followers of our facebook page, which is an increase of 18% in the past 16 months to November 2018. The Australian Facebook discussion group we host has 800 followers. Our recent Q&A with Dr Hagerman facebook videos have been widely shared and viewed 000's of times.



21,489 views of our youtube videos 2017-18 is consistent with the previous year. Highlights: 17,500 views of the two Understanding FX videos; 566 views of Q&A with Dr Braden; 400 views of 'When to consider a Fragile X diagnosis' with Dr Jonathan Cohen. We have 180 subscribers.



700 followers of our Twitter account, an increase of 16% over the past 12 months. We tweet when we have news and information resources to share, and we follow organisations in the health, genetic and intellectual disability areas for the latest news.



At **377** followers, our Instagram following has more than doubled over the past 16 months to November 2018.

Fragile X disorders—Don't miss them

Diagnosis of Fragile X: Parental concern an important indicator for GPs

This article on the importance of responding to parental concern was prepared by FXAA and based on interviews with a number of specialist doctors.

While the article was written specifically for GPs it is equally as relevant to all other health professionals who have early and ongoing contact with mothers and their young children. The article also appeared in the FX Info newsletter and on www.fragilex.org.au

When presenting on the topic "What GPs need to know about intellectual disability", **Professor Stewart Einfeld**, Centre for Disability Research and Policy, University of Sydney, said that parental concern is enough to indicate further testing.

And according to A/Professor Natalie Silove, consultant paediatrician and Head of Child Development Unit, The Children's Hospital at Westmead, research shows that parents have an 80% chance of being correct. In other words, if parents express concern about their child's development then in 80% of cases, assessment will confirm their instincts are right.

Professor Einfeld believes that a healthcare professional's threshold for responding to parental concern should be low. When faced with parents who are concerned about their child's development, current best practice for GPs is to take notice and listen, and if suitably trained, conduct a baseline developmental screening tool such as the Parents' Evaluation of Developmental Status (PEDS) or the Ages and Stages Questionnaire. Alternatively, a GP should refer to a paediatrician or community health centre.

"It is important to take action when a parent expresses concern, and the use of a screening tool helps by doing something tangible to show the parent their child's developmental progress relative to other children of the same age," says Professor Silove. Follow-up is also essential, even if the child is not showing signs of developmental delay as this will provide further reassurance to the parents.

It is very important that health professionals do not provide false reassurance to parents who express concern about their child's development. This can make parents very angry and feel let down, particularly when they are aware that opportunities for early intervention may have been missed.

Think GP "If REED MEDICAL education

Prepared by Fragile X Association of Australia for publication on the ThinkGP education portal of Reed Medical Education in July 2017.

GPs are not trained to conduct developmental screening or are not sure how to manage the situation, do not disregard the parents' concerns but take action and refer on. There is nothing lost by providing parents with access to assessment," says Professor Einfeld.

Changes in NSW

However, there are changes afoot to help accelerate the early identification of development delay, specifically in NSW where the current system for developmental surveillance is run by child and family nurses using the PEDS, part of the infamous 'blue book'. As nowadays only 30% of parents visit the child and family nurse after the child turns one, opportunities for early identification are less frequent.

Professor Valsamma Eapen, chair, Infant Child and Adolescent Psychiatry at UNSW, is conducting a research project with NSW Health and Liverpool Hospital in South West Sydney looking at using the opportunistic contact with a health professional during vaccination visits to facilitate early identification of developmental problems.

Professor Eapen's trial using the **Watch Me Grow** webapp is targeting parents who are visiting the GP as part of the routine 12 or 18 month vaccination schedule. While in the waiting room, parents are given an ipad to access the webapp to answer 17 questions – 7 relating to general development and 10 specific to autism. Once completed, and before the appointment begins, the results are analysed and any parent-reported concerns along with recommendations such as refer for further assessment, early intervention etc are communicated to the GP.

The parent will also receive an email with feedback on the results along with anticipatory guidance linked to the US-based Center for Disease Control and Prevention (CDC) Learn the signs. Act Early program which provides a summary of milestones for children aged from 2 months – 5 years, and provides the tools for parents to track their child's development and act early on any concerns. This is in keeping with the recent changes made by NSW Health regarding developmental surveillance in the 'blue book' where the PEDS has been replaced by Learn the Signs. Act Early resources. Professor Eapen is hoping to receive funding for a larger, multi-site trial to continue validating the program.

Diagnosis: A Personal Story

Helen Tozer is the parent of Josiah, a six year old boy with Fragile X syndrome. With a background in early childhood education, she knew that Josiah was not meeting his developmental milestones from a very young age.

She first raised her concerns with a GP in Hong Kong when Josiah was one month old but her concerns were brushed aside and she was told that he was fine. After a move to the USA and escalating anxiety about Josiah's development, Helen become increasingly proactive in finding a health professional who would take her concerns seriously and act on them accordingly.

"At first, I felt like I needed to justify my concerns and convince the doctor that I was right about my son," Helen said.

"The doctor eventually agreed with me which started a diagnostic treadmill that, after endless inconclusive neurological and metabolic testing, finally resulted in genetic testing and the diagnosis of Fragile X syndrome when Josiah was 18 months old."

Helen says that she and her husband were told multiple times by both health professionals and other parents that boys tend to be more delayed than girls.

Prepared by Fragile X Association of Australia for publication on the ThinkGP education portal of Reed Medical Education in July 2017.



"Not only is this untrue but being continually told that boys are slower to develop is disempowering and undermines a parent's level of concern," said Helen.

When asked if she had advice for other parents who are concerned about their child's development, Helen says to trust your instincts and don't give up.

She acknowledges that not everyone is an "instinctive advocate" but urges parents to keep searching for a health professional who acknowledges that your concerns are valid and is prepared to work with you to confirm or deny them.

Photo of the Tozer family for Fragile X Association of Australia by Daniel Linnet of LinnetFoto

Fragile X disorders—Don't miss them

It is still the case that **Fragile X-associated disorders** are not always identified as early as they could be: they remain "**frequently under-recognised and often misdiagnosed**."

Early diagnosis of Fragile X syndrome, FXTAS and FXPOI provides opportunities for early intervention, early treatments and the best health outcomes.

Increasing awareness of Fragile X-associated disorders in the medical community remains an important priority. We actively pursue opportunities to achieve this. We have a regular presence at the women's health and general education days run by Healthed in the main capital cities each year. This gives thousands of general practitioners regular exposure to information about testing and diagnosis of Fragile X-associated disorders. Further, we have presented several times at a regular expo for medical students at UNSW, and we will be presenting to students in Masters of Genetic Counselling programs in 2019.

Many thanks to our members who volunteer their time to represent us at Healthed conferences and other opportunities to increase awareness of Fragile X.









¹ Fragile X-associated Disorders: Don't miss them, Rachael C Birch, Jonathan Cohen, Julian N Trollor. Australian Family Physician, Vol 46, No 7, July 2017. p487-491. Available online at www.racgp.org.au/afp/2017/......

Fundraising Highlights

Our members and supporters do a wonderful job in using community events to increase awareness of Fragile X-associated disorders and to fundraise for us. Fundraising is an important way to generate the income to support our day-to-day operations and new initiatives.







For the 5th year in a row FXAA was sole charity partner for the annual Bridge to Beach paddle race. This iconic race is an 11km paddle across Sydney Harbour, from just under the Bridge and across the Harbour to end at Manly Cove. The race is run by Oceanpaddler, a local business founded by world champion paddler Dean Gardiner. \$10,000 was raised for FXAA through the race fundraising. Generously matched, dollar for dollar, by Shaw & Partners Foundation this resulted in an lamazing \$20,000 to help fund our Family Support role. Mackenzie "Macca" Hynard took out race honours in fasntastic time, and has kindly agreed to be Fragile X ambassador for Bridge to Beach 2019 in February!

Cheque presentation at Manly Cove after the race.

Mackenzie Hynard (Shaw & Partners Race Team), Graham Hook (FXAA), Earl Evans (Co-CEO of Shaw & Partners)







Sydney's City2Surf is a 14km running challenge—from the starting point in Hyde Park and on to Bondi Beach.

"Fast Suit Guy" **Mike Tozer** and **Cynthia Roberts** put in an amazing performance, raising over \$20,000 in their back to back efforts in 2017 and 2018!





Mike Tozer was keen for a second Guinness World Record! This time he took on a full marathon—42km around Sydney finishing up on the steps of the Opera House. Mike set a cracking pace and achieved an amazing 2hr 50min, but unfortunately was pipped at the post by another runner in a suit..... Mike and his son Josiah were invited to appear on Studio 10, ahead of the race, to talk about Fragile X syndrome and why it is that Mike runs in the blue suit with the ever-present orange ribbon.



Workshops and Seminars

FRAGILEX COMMUNITY DAY Wednesday 1 November 2017 Friday 3 November 2017

Dr Marcia Braden and Dr Jonathan Cohen led two full-day Fragile X Community Day workshops hosted by FXAA in Brisbane and Hobart. The program covered strategies to support the Fragile X learning style, daily living and successful supports, and an update on the latest on Fragile X-associated conditions.

In Brisbane speech pathologist Melinda Cassells presented on supporting language development, and in Hobart neurodevelopmental optometrist Rashelle Cohen presented on vision and sensory issues in Fragile X.

Dr Marcia Braden is an educational psychologist from **Videos** of presentations from the Brisbane Fragile X the US who specialises in educational strategies and behaviours in children and adults with Fragile X syndrome, and Dr Jonathan Cohen is the medical director of the Fragile X Alliance Clinic in Melbourne. It was our pleasure to partner with them again to present the Fragile X Community Days, both of which were very well attended. Assessment clinics were conducted by Dr Braden and Dr Cohen in conjunction with the workshops.

Community Day are available on our FXAA youtube channel. Each video has been viewed several hundred times by an Australian and international audience. Our thanks to the telco Chorus Call for the chance to win a grant to support the Community Days, and our thanks to Calvary Hospital Foundation in Tasmania for a grant to support the workshop and clinics, and to Tony Brennan for welcoming us to Hobart and formally opening the workshop.







Prof Randi Hagerman was keynote speaker at evening seminars hosted by FXAA at the Royal Children's Hospital (Melbourne), and the Garvan Institute of Medical Research (Sydney), in August & September 2018. Both events were very well attended with audiences including families, genetic counsellors, researchers, medical students and other health professionals. Dr Hagerman had a full schedule during her short visit! She saw several patients, opened the new FXTAS clinic at Caulfield Hospital, gave a lecture on FX premutation at MCRI, met with clinicians with an interest in FXTAS, and made several Q&A videos for our youtube channel and social media.

Many thanks to Dr Hagerman for generously giving so much of her time, and to **Zvnerba Pharmaceuticals** for a grant to meet FXAA's associated costs.



Dr Sam Bolitho, A/Prof Stephen Tisch (St Vincent's), Prof Randi Hageman, Prof Ted Brown (FXAA)



Mr John Cunningham, Prof Randi Hagerman

Financial Overview

During the financial year 1 July 2017 to 30 June 2018, the net assets of Fragile X Association of Australia (FXAA) were largely unchanged from the previous year. Income for the operations of the organisation included continued generous financial support from the Cunningham family, funds raised by our members and supporters, and the final tranche of a 3-year grant from a private philanthropic foundation.

Net assets of approx. \$700,000 largely comprise the Endowment Fund of approx. \$600,000, which underlies FXAA's financial stability but is not available for operations.

As foreshadowed in last year's annual report, a 3-year grant of \$100,000 per annum from a philanthropic foundation which has been a generous long-term supporter of FXAA concluded. Planned spending reductions, including rental costs, were implemented accordingly. These cost savings have allowed for FXAA's operations to be maintained, while producing a small surplus for the year.

As FXAA receives no government funding or fees from services, it depends on the goodwill of supporters and sponsors to remain viable. This is forthcoming from year to year but is not guaranteed and is always somewhat unpredictable. Further, as membership fees have been waived to encourage membership growth, this revenue source must be replaced.

2019 marks **FXAA's 30th year** as a national body and will be a catalyst for raising the profile of Fragile X and expanding our support base.

We are very fortunate to have **Shaw and Partners** as an active corporate sponsor. In 2018 the Shaw and Partners Foundation matched funds raised for FXAA through Oceanpaddler's Bridge to Beach race in Sydney, and is also matching another donor's contribution to our film project The Fragile X Factor.

We are also most appreciative of the many individuals and groups who raise funds for FXAA in different ways. Firstly, on the running side: many thanks to **Cynthia Roberts** for her annual fundraising through the City2Surf fun run in Sydney; and congratulations to **Mike Tozer** for raising funds and media coverage through participation in a variety of events for Fragile X, ranging from family fun runs to the truly elite challenge of running a full marathon in a suit!

Community support is also very important in raising the funds needed to sustain our services. The annual collaboration between the **Galston Garden Club** and **Masonicare** results in a significant donation to FXAA; the Dixon's Creek annual community concert in 2017 chose to support Fragile X; and the Launceston community has established a well-attended annual fundraising High Tea for FXAA.

Thanks must go to everyone who helps raise funds, small and large, to sustain FXAA; every donation makes a difference.

In this new financial year of 2018/2019 we received an entirely unexpected and sizeable donation from a private individual, and we intend to build new relationships encouraging potential donors to choose FXAA as a worthy 'cause' to support. It is important to have a compelling case and ensure that donors can see the impact of their financial support - this will be a core focus for 2019.

Meantime FXAA's **Endowment Fund** ensures financial surety for FXAA as a 'reserve' with the intended future role of generating sufficient return for use in operations, which was the Fund's original purpose. Conservative investment during the year yielded a net return of nearly 6%. The Endowment Fund Committee's chairman, David Bassingthwaighte, retired from this role on 30 June 2018 and is very warmly thanked for his enormous contribution in shepherding the Endowment Fund and in bringing significant financial support into FXAA. We are very pleased that David's colleague on the Endowment Fund Committee, Martin Davey, has agreed to take on the chairmanship and ensure continuation of prudent management. Other members of the Endowment Fund Committee remain the FXAA Secretary and Treasurer, together with former Board member John Kelleher who also serves as an active advisory member of the FXAA Board's executive committee.

We remain very grateful for the ongoing support of Mr Peter Vilimaa and the firm Manser, Tierney and Johnston who have provided pro bono auditing services to FXAA for many years. The Board and our staff wish to record their great appreciation of this long-term support and invaluable input, which provides excellent independent scrutiny and oversight of FXAA's financial affairs. We commend to members the re-appointment of Mr Peter Vilimaa of Manser, Tierney & Johnston as auditor.



FINANCIAL STATEMENTS 30 JUNE 2018

DECLARATION BY MEMBERS OF THE COMMITTEE

In accordance with a resolution of the committee of Fragile X Association of Australia Inc the members of the committee declare that:

- 1. the attached financial statements comprising the statement of financial position as at 30 June 2018, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended and notes to the financial statements, present a true and fair view of the financial position of Fragile X Association of Australia Inc as at 30 June 2018 and its financial performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements, the requirements of the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Act 2012; and
- 2. at the date of this statement, there are reasonable grounds to believe that Fragile X Association of Australia Inc is able to pay all of its debts, as and when they become due and payable.

This declaration is signed in accordance with subsection 60.15(2) of the *Australian Charities and Not-for-profits Commission Regulation 2013.*

JUDITH LENART

Treasurer and Co-ordinator of the Board

CHRISTINE KELLEHER

Secretary

Dated this 201h day of October 2018.



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

Report on the Audit of the Financial Report

We have audited the financial report of Fragile X Association of Australia Inc (the association) which comprises the statement of financial position as at 30 June 2018, the statement of profit or loss and other comprehensive income, statement of changes in equity and statement of cash flows for the year then ended, and notes to the financial statements, including a summary of significant accounting policies, and the declaration by members of the committee.

Opinion

In our opinion, the accompanying financial report of Fragile X Association of Australia Inc has been prepared in accordance with the *Associations Incorporation Act 2009 (NSW)* and Division 60 of the *Australian Charities and Not-for-profits Commission Act 2012*, including:

- a) giving a true and fair view of the association's financial position as at 30 June 2018 and of its financial performance for the year then ended; and
- b) complying with Australian Accounting Standards to the extent described in Note 1 to the Financial Statements and Division 60 of the *Australian Charities and Not-for-profits Commission Regulation 2013*.

Basis for Opinion

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's Responsibilities* for the Audit of the Financial Report section of our report. We are independent of the association in accordance with the ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110: Code of Ethics for Professional Accountants (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Emphasis of Matter – Basis of Accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the association to meet the requirements of the *Associations Incorporation Act 2009 (NSW)* and for the purpose of fulfilling the association's financial reporting requirements under the *Australian Charities and Not-for-profits Commission Act 2012*. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Taxation & Business Advice • Self Managed Superannuation
Audit & Assurance • Wealth Management



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

Responsibilities of the Committee for the Financial Report

The committee of the association is responsible for the preparation of the financial report that gives a true and fair view and have determined that the basis of preparation described in Note 1 of the Financial Statements is appropriate to meet the requirements of the Associations Incorporation Act 2009 (NSW) and the Australian Charities and Not-for-profits Commission Act 2012. The committee's responsibility also includes such internal control as the committee determines is necessary to enable the preparation of a financial report that gives true and fair view and is free from material misstatement, whether due to fraud or error.

In preparing the financial report, the committee is responsible for assessing the association's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the committee either intends to liquidate the association or to cease operations, or have no realistic alternative but to do so.

Auditor's Responsibilities for the Audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

As part of an audit in accordance with Australian Auditing Standards, we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial report, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the association's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the committee.

Taxation & Business Advice • Self Managed Superannuation
Audit & Assurance • Wealth Management



INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF FRAGILE X ASSOCIATION OF AUSTRALIA INC

- Conclude on the appropriateness of the committee' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the association's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial report or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the association to cease to continue as a going concern.
- > Evaluate the overall presentation, structure and content of the financial report, including the disclosures, and whether the financial report represents the underlying transactions and events in a manner that achieves fair presentation.

We communicate with the committee regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Signed at Wahroonga this

day of October

MTJ AUDIT PTY LTD

PETER VILIMAA

Registered Company Auditor 312147

MTJ Audit Pty Ltd ABN 79 612 252 310

Taxation & Business Advice • Self Managed Superannuation Audit & Assurance • Wealth Management

Fax. 02 9487 2109 Web. www.mansertj.com.au

STATEMENT OF FINANCIAL POSITION AS AT 30 JUNE 2018

	Note	2018	2017
CURRENT ASSETS			
Cash on hand			
At Bank		78,182	62,230
Bank Guarantee	0	-	6,875
Endowment Fund	8	244,422	251,745
Petty Cash			104
A		322,604	320,954
Accounts receivable and other debtors		40.000	6.750
Accounts Receivable Accrued Income		10,898 12,520	6,750
Franking Credits Refundable		4,494	6,556
GST Refundable		9,019	10,036
Prepayments		3,805	10,030
Rental Bond		3,416	3,416
Northal Borta		44,152	26,758
TOTAL CURRENT ASSETS		366,756	347,712
NON-CURRENT ASSETS Property, plant and equipment			
			21,811
Office Equipment - At Cost		-	(17,321)
Less: Accumulated Depreciation			4,490
Investments		-	4,430
Listed Investments at Market Value - Endowment Fund	8	359,815	308,795
TOTAL NON-CURRENT ASSETS		359,815	313,285
TOTAL ASSETS		726,571	660,997
		720,071	
CURRENT LIABILITIES			
Accounts payable and other payables		(15)	9 100
Accounts Payable Accrued Expenses		(15) 500	8,190
Income Received in Advance		420	1,475
Payroll Liabilities		8,776	2,673
Other Liabilities		4,274	865
Other Elabilities		13,955	13,203
Provisions		10,900	13,203
Provision for Employee Entitlements		5,305	8,027
TOTAL CURRENT LIABILITIES		19,260	21,230
TOTAL LIABILITIES		19,260	21,230
NET ASSETS		\$707,311	\$639,767
EQUITY			
		639,767	333,472
Opening Balance		67,544	306,295
Add: Surplus for the Year			
TOTAL EQUITY		<u>\$707,311</u>	<u>\$639,767</u>
The accompanying notes form part of these financial	al etatemor	ite	

The accompanying notes form part of these financial statements.

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2018

	2018	2017
INCOME		
Gross Proceeds From Fundraising Appeals		
Christmas Cards	68	644
Conference Income	3,076	-
Donations - including Endowment Fund	270,913	561,007
FXAA Fundraising Events and Appeals	30,315	8,174
Merchandise Sales	720	75
Raffle Sales		2,085
	305,092	571,985
Other		
Dividend Income	22,736	14,108
Grants	9,091	-
Interest	4,557	1,517
Subscriptions	3,675	1,525
	40,059	17,150
Total Income (carried forward)	345,151	589,135

STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME FOR THE YEAR ENDED 30 JUNE 2018

	2018	2017
Total Income (brought forward)	345,151	589,135
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Card Day	-	6
Other	9,028	8,333
	9,028	8,339
Total Costs Of Providing Services		
Support Services and FX Awareness	57,002	29,500
Clinics and Counselling	30,650	43,558
National Newsletter Printing	2,619	4,862
,	90,271	77,920
Other		
Bank Fees and Charges	1,525	2,048
Board and AGM Expenses	620	1,167
Conferences and Seminars	27,603	6,079
Consultants	11,723	51,493
Depreciation and Disposal of Assets	5,005	2,077
Donations	_	5,000
General Administration - Employment Costs	80,665	78,565
Insurance	4,880	4,406
Loss on Sale of Investments	2,929	-
Office Expenses	10,216	9,927
Office Rent	20,166	31,472
Office Relocations Costs	9,384	-
Postage	3,113	3,105
Provision for Employee Entitlements	(2,721)	256
Stationery	1,399	4,671
Subscriptions	3,315	1,229
Sundries	1,035	251
Telephone	4,566	4,463
	185,423	206,209
Total Expenditure	284,722	292,468
OPERATING SURPLUS FOR THE YEAR	60,429	296,667
Increase/(Decrease) in value of investments - Endowment Fund	7,115	9,628
TOTAL COMPREHENSIVE INCOME FOR THE YEAR	\$ 67,544	<u>\$306,295</u>

STATEMENT OF CHANGES IN EQUITY FOR THE YEAR ENDED 30 JUNE 2018

	2018	2017
EQUITY		
Retained Earnings		
Opening Balance 1 July Add: Surplus for the Year Closing Balance 30 June	640,688 60,429 701,117	344,021 296,667 640,688
Asset Revaluation Reserve		
Opening Balance 1 July Add: Transfer to/(from) Reserve Closing Balance 30 June	(921) 7,116 6,195	(10,549) 9,628 (921)
TOTAL EQUITY	<u>\$707,312</u>	\$639,767

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 30 JUNE 2018

		2018	2017
Cash Flow from Operating Activities			
Receipts from fundraising appeals and events Payments to suppliers and employees		361,425 (296,016)	588,107 (304,538)
Net cash provided by operating activities	10b	65,409	283,569
Cash Flows from Investing Activities			
Payment for property, plant and equipment Payment for other investments		(1,611) _(62,148)	- (55,468)
Net cash used in investing activities		_(63,759)	(55,468)
Net Increase/(decrease) in Cash Held Cash on hand at the beginning of the financial year		1,650 320,954	228,101 92,853
Cash on hand at the end of the financial year	10a	<u>\$322,604</u>	\$320,954

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

Note 1 – Summary of Significant Accounting Policies

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the *Associations Incorporation Act 2009 (NSW)* and the *Australian Charities and Not-for-Profits Commission Act 2012*. The committee has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values, or except where specifically stated, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of these financial statements.

a) Income Tax

No provision for income tax has been raised, as the association is exempt from income tax.

b) Property, Plant and Equipment

Property, plant and equipment are carried at cost, independent or committees' valuation. All assets, excluding freehold land and buildings, are depreciated over their useful lives to the association from the time the asset is held ready for use.

c) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, an impairment test is carried out on the asset by comparing the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised in the income and expenditure statement.

d) Employee Provisions

Provision is made for the association's liability for employee benefits arising from services rendered by employees to the end of the reporting period. Employee provisions have been measured at the amounts expected to be paid when the liability is settled.

e) Provisions

Provisions are recognised when the association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliably measured. Provisions are measured at the best estimate of the amounts required to settle the obligation at the end of the reporting period.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

Note 1 – Summary of Significant Accounting Policies (cont'd)

f) Cash on Hand

Cash on hand includes cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

g) Accounts Receivable and Other Debtors

Accounts receivable and other debtors include amounts due from members as well as amounts receivable from donors. Receivables expected to be collected within 12 months of the end of the reporting period are classified as current assets. All other receivables are classified as non-current assets.

h) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable.

Interest revenue is recognised using the effective interest rate method.

Grant and donation income is recognised when the entity obtains control over the funds which is generally at the time of receipt.

All revenue is stated net of the amount of goods and services tax (GST).

i) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Tax Office (ATO). Receivables and payables are stated inclusive of the amount of GST receivable or payable. The amount of GST recoverable from, or payable to, the ATO is included with other receivables in the Balance Sheet.

i) Financial Assets

Investments in financial assets are initially recognised at cost, which includes transaction costs and are subsequently measured at fair value which is equivalent to their market bid price at the end of the reporting period. Movements in fair value are recognised through an equity reserve.

k) Account Payable and Other Payables

Accounts payable and other payables represent the liability outstanding at the end of the reporting period for goods and services received by the association during the reporting period that remain unpaid. The balance is recognised as a current liability with the amounts normally paid within 30 days of recognition of the liability.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

Note 1 – Summary of Significant Accounting Policies (cont'd)

I) Member's Liability

Members are liable for the amounts each member owes the association in respect of their membership ie fees or subscriptions due to the association.

Members of the management committee of the association also have limited liability for the debts of the association, as long as they have followed accepted business and community standards.

m) Comparative Figures

Where required by Accounting Standards, comparative figures have been adjusted to conform with changes in presentation for the current financial year.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

Note 2 - Information on Material Matters

The Association received \$110,000 from the Cunningham family.

Note 3 - Application of appeal monies

During the year the Association received net income of \$305,092 from fundraising appeals, \$27,293 from the investment of appeal monies, \$3,675 from membership fees and \$9,091 from a grant.

An amount of \$90,271 was spent on the provision of services (including \$30,650 for clinics and counselling, \$2,619 for newsletters, and \$57,002 for other awareness and support). We spent \$116,927 on rent, insurance, administration, office expenses and \$9,384 on the office relocation. We spent \$27,603 on conferences and seminars. We also spent \$11,723 on a medical marketing project to raise awareness in the medical community.

Note 4 - Information on traders

The Association did not use traders in carrying out fundraising appeals.

Note 5 - Fundraising appeals conducted during the period

Appeals conducted were:

- Soliciting of donations
- Bridge to Beach 2018
- Fun runs
- Fragile X Awareness day events
- FX Community Days with Dr Marcia Braden

Note 6 - Analysis of monetary figures

Ratios	\$	%
Total cost of fundraising/	9,028/305,092	3% (1.3% last year)
Gross income from fundraising Net surplus from fundraising/	296,064/305,092	97% (99% last year)
Gross income from fundraising Total costs of services/	90,271/185,423	48% (28% last year)
Total expenditure Total costs of services/ Total income received	90,271/345,151	26% (13% last year)

Note 7 - Commitments

No material commitments were entered into by the association during the year.

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

Note	2018	2017
Note 8 - Endowment Fund Balance Sheet - as at 30 June		
CURRENT ASSETS Cash on hand		
At Bank	16,260	80,005
Investments maturing within 3 months Term Deposits	- 228,162	71,740 100,000
	244,422	251,745
Accounts receivable and other debtors Franking Refund Receivable	4,494	6,556
TOTAL CURRENT ASSETS	248,916	258,301
NON-CURRENT ASSETS Investments	210,010	
Listed Investments - At Market Value	359,815	308,795
TOTAL NON-CURRENT ASSETS	359,815	308,795
NET ASSETS	\$608,731	<u>\$567,096</u>
EQUITY		
Opening Balance	567,096	284,252
Add: Income for the Year 9	41,635	_282,844
TOTAL EQUITY	\$608,731	<u>\$567,096</u>
Note 9 - Endowment Fund Income & Expenditure Statement - for the year ended 3	0 June	
INCOME		
Dividend Income	22,736	14,108
Donations Increase in Market Value of Investments	11,092 7,115	258,720 9,628
Interest	3,621	388
Less:	44,564	_282,844
Loss on Sale of Investments	2,929	_
	2,929	
NET INCOME FOR THE YEAR	\$ 41,635	\$282,844

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2018

	2018	2017
Note 10 - Cash Flow Information		
(a) Reconciliation of Cash		
Cash at the end of the financial year as shown in the statements of cash flows is reconciled to the related ite in the statement of financial position as follows:	ms	
Cash at bank	322,604	320,954
(b) Reconciliation of cash flow from operations with profit from ordinary activities		
Operating Surplus/(Deficit) Non-cash flows in Operating Surplus/(Deficit) - Depreciation - (Gain)/loss on sale of investments	60,429 5,005 2,929	296,667
Changes in assets and liabilities - (Increase)/decrease in receivables - (Increase)/decrease in other assets - Increase/(decrease) in payables - Increase/(decrease) in other current liabilities - Increase/(decrease) in provisions	(4,148) (13,246) 8,205 8,957 (2,722)	(2,617) (7,779) (3,919) (1,116) 256
Net cash provided by operating activities	\$ 65,409	\$ 283,569



Support Us

Make a Tax-Deductible Donation www.givenow.com.au/fragilex

A strong member base increases our voice and grows our network

Workplace Giving
Introduce us to your workplace giving program

Fundraise
Organise a fundraising event

Connect with us
Follow us on Facebook, Twitter, Instagram and YouTube

Partner with us
Find out how your organisation can partner with us in supporting
the Fragile X community

CONTACT US

1300 394 636 (cost of local call) support@fragilex.org.au

Registered office: Suite 204, 20 Dale Street, Brookvale NSW 2100

ABN 18 655 264 477

ARBN 626 478 966

